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After the top 10: Bringing community priorities to life

It's been over a year since the final workshop of our neurodevelopmental disorder Priority Setting Partnership (PSP). This seminal moment marks the day when patients, family members, and front-line care providers came together and reached consensus on a top 10 list of research priorities for the research community. While all PSP initiatives culminate in a final workshop, we've been working hard to spread the word about the top 10 and address the community's priorities.

Spreading the word

We've spent the past year promoting the top 10 priorities and ensuring that they reach the right audiences. This includes researchers studying neurodevelopmental disorders, organizations that fund research, the community, and general public.



Community Priorities for Research
on Neurodevelopmental Disorders

Final report

In August we released a report on the Community Priorities for Research on Neurodevelopmental Disorders. The report provides a step-by-step breakdown of the priority setting process and the resulting top 10 priorities. [Read the report.](#)

SHAPING THE FUTURE OF NEURODEVELOPMENTAL DISORDER RESEARCH

We received 1200+ questions from individuals, families, carers, and health/education professionals about interventions for neurodevelopmental disorders. We then asked them to rank which questions were most important to them. Here are the top 10 research priorities from the neurodevelopmental disorder community.

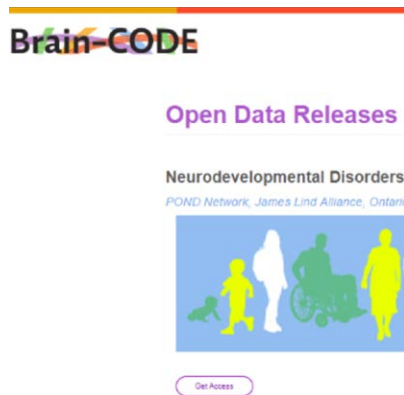
TOP 10 RESEARCH PRIORITIES FOR NEURODEVELOPMENTAL DISORDERS

1. What are the most effective treatment options/plans (e.g., timing, frequency, duration, type, intensity or dosage) for individuals with neurodevelopmental disorders for both short and long-term benefits?
2. How can system navigation be organized in a manner that enables coordinated services and supports across the lifespan for individuals with neurodevelopmental disorders and their families?
3. Which biological treatments (including medications, gene therapy, stem cell therapy, etc.) are effective for neurodevelopmental disorders and associated symptoms?
4. Which child and family-centred
5. Which
6. Which resources are needed to more effectively address the health, social and emotional needs of families or caregivers of individuals with neurodevelopmental disorders?
7. How can treatment decisions for individuals with neurodevelopmental disorders be more precise (i.e., based on the diagnosis, age, functional need of the individual)?
8. Which are the most effective pharmacological and non-pharmacological treatments for aggressive and self-injurious behaviour in individuals with neurodevelopmental disorders?
9. Which are the most effective

Infographic

After the final workshop we released an infographic of our top 10 research questions and shared it widely through our networks and social media channels. [Download and share this with your network to help us continue the conversation.](#)

Open data release



We released a research database that holds over 1200 original questions that were asked by the community. The database that can be accessed and explored by researchers, patients and families alike. [Explore the data.](#)



Presentations

We have been presenting the top 10 at international academic conferences to raise awareness and create interest within the neurodevelopmental disorder research community. [See what and where they have presented.](#)

Addressing the priorities

The [Province of Ontario Neurodevelopmental Disorder Network \(POND\)](#) is an integral partner in the neurodevelopmental disorder PSP. POND's main goal is to improve treatments and long-term outcomes for people with neurodevelopmental disorders. The top ten research priorities of the neurodevelopmental community overlap with some of POND's current research. For example, the top ranked priority of the NDD community is to understand the most effective treatment plans/options for short and long-term benefits. This is still a difficult question to answer because the cause, or underlying biology, can be different in people with the same diagnosis. POND has developed the first clinical trial network in Canada dedicated towards neurodevelopmental disorders. Clinical, behavioural, and molecular data is collected for every participant in this network. By collecting this data, a unique opportunity to understand the effectiveness of various treatments presents itself.

Here are a few more examples of how POND is addressing some of the top 10 questions posed by the community:

Priority 3



Which biological treatments (including medications, gene therapy, stem cell therapy, etc.) are effective for neurodevelopmental disorders and associated symptoms?

Clinical trials for new treatments are always tested through several phases. Phase I tests initial safety and

dosage of a medication. Phase II tests the first time potential efficacy and further evaluates safety, and Phase III is the definitive stage to evaluate whether an intervention works. How effective a treatment is (Priority 3) is an important question; POND recently completed a [Phase II clinical trial](#) to test the effectiveness of a drug called Tideglusib, a drug previously used for Alzheimer's disease. Youth with autism treated with the drug showed improvements in social skills as well as other symptoms related to memory, repetitive behaviours, sleep quality and daily living skills.

Priority 7



How can treatment decisions for individuals with neurodevelopmental disorders be more precise (i.e., based on the diagnosis, age, functional need of the individual)?

Matching people to the right treatment plan is a [major goal for POND](#). By understanding the underlying biology of children and youth with neurodevelopmental disorders, more comprehensive and effective treatment plans can be developed and administered. All the clinical trials include genetic and imaging information to further our understanding of which intervention is right for whom. In fact, POND is also using patient skin and blood samples to create cells lines that can be used for drug screening and predict a patient's response to treatment.

Priority 9



Which are the most effective pharmacological and non-pharmacological intervention(s) to reduce anxiety in individuals with neurodevelopmental disorders?

One major undertaking to address anxiety has been through the development of a technological intervention. POND researchers have developed, patented and clinically validated an anxiety meter algorithm that uses heart rate to determine a patient's anxiety level. This technology is extremely useful in helping both the individual and their care team identify and manage anxiety. Recently, POND partnered with [Awake Labs](#) to integrate this technology with their wearable platforms and test its use in real-world settings. This [pilot](#) will be the first step towards making this empowering tool more accessible to those who need it.

We have made progress over the last year to promote the priorities and begin addressing them through research. But there is more work needed to ensure the voice of the community is reflected in research questions being asked.

Stay tuned as we continue to bring the community priorities to life.



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